

309 First results of health status assessment in children with cystic fibrosis using Russian version of HUI Questionnaire

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Introduction: Quality of life (QoL) measurement in cystic fibrosis (CF) should quantify and evaluate the impact of both the disease and its treatments on the wider aspects of patients' life.

Aim: To determine the impact of the disease and treatment on health status in children with CF.

Objectives: 45 children aged 5–17 yrs with moderate and severe forms of CF were interviewed using a questionnaire of the HUI version 15Q which has been translated into Russian and adapted. For children >12 the self assessment version was used, for children <12 years – proxy assessment. A comparison of health status was conducted against the background of the therapy in 2 weeks of the dynamics (n=14).

QoL assessment was carried out on systems HUI 2 and 3. Single-attribute utility scores and multi-attribute utility scores evaluated corresponding to each system range from 0 (death) to 1 (full health).

Results: Significant differences were obtained between patients with moderate and severe forms:

Single-attribute utility scores HUI 3: Ambulation (p=0.012), Pain (p=0.008).

Single-attribute utility scores HUI 2: Mobility (p=0.012), Emotion (p=0.023).

Multi-attribute utility scores (children/parents): HUI 3 (p=0.008) and HUI 2 (p=0.016).

Significant differences were obtained against the background of therapy in single-attribute utility scores HUI 2: Emotion; (p=0.049) and multi-attribute utility scores (p=0.023).

Conclusion: Ambulation, pain and emotion have more influence on health status in CF children. It's established that at the background of therapy emotion factor responds primarily.

311 Barriers and motivations for the decision of pulmonary transplantation in cystic fibrosis patients

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Introduction: Representations of patients about transplantation are among factors that might influence their decision: negative representations could constitute a loss of chance for the patients.

Objectives: To describe representations, to identify those which would constitute barriers or motivations for transplantation and to identify educational needs.

Methods: A concept map is realised during an interview with 30 adult patients, candidates for transplantation (18 men, 12 women, medium age=29 years) from 19 French centers. On their concept map, patients identify elements that constitute barriers or motivations for transplantation.

Results: Representations are distributed into three large domains: before transplantation, during intervention and after transplantation. Patients in each domain identify barriers and motivations.

Before transplantation, barriers are essentially: current health status (7), waiting for transplantation (4). About intervention, barriers are: risks (15), indications (8), consequences for the patient (8), waking up after surgery, pain (6). After transplantation, barriers are: being in front of another disease (9). Other barriers: lack of knowledge in transplantation (7).

Motivations are mainly evoked after transplantation: possibility of projects (26), improvement of health (17).

Conclusion: Educational needs have to be extracted to improve preparation of transplantation: improving knowledge, coping with fears and emotions. The study is ongoing to analyse representations of patient relatives and those of doctors.

This study is supported by Vaincre la mucoviscidose.

310 The emotional context of self-management in cystic fibrosis: young adults and their parents' experiences

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Background: The concept of self-management is embedded in many healthcare policy and strategy initiatives concerning chronic illness management, and a growth of self-management programmes is now evident in the literature. However, self-management can be complex involving more than disease management. Although emotional management of illness needs to be integral to self-management programmes (Lorig & Holman 2003), this has received little attention within the context of cystic fibrosis (CF) to date as evident in a recent Cochrane review (Savage et al. 2011).

Aims/Objectives: This paper explores the emotional context of self-management experiences of young adults with CF and their parents.

Methods: In-depth qualitative interviews with 13 young people with CF (aged 13–22 yrs) and their parents were conducted. The sample was drawn from 2 CF centres in Ireland. Data were analysed using the constant comparative method to explore the issues of central relevance to young adults and their parents.

Results: Young people described self-management as an 'emotional labour' that could be positive or negative and that impacted significantly on their social lives and future aspirations. Parents grappled with supporting their children at an emotional level and were often at a loss in communicating with their children about their concerns.

Conclusions and Implications: The implications point to a need to focus on positive emotional health and well-being as an integral component of self-management. The data provide useful insights into developing critical components of a self-management intervention for CF care that encompasses emotional as well as disease management.

312 The course of perceived treatment burden in adolescent and adult CF patients

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Objectives: The prognosis of cystic fibrosis increased over the last years. The complex therapy requires increasing time and effort of the patients, which can affect perceived treatment burden, have a negative impact on quality of life and might reduce adherence. Purpose of the study was to evaluate changes in perceived treatment burden related to lung function in adolescent and adult CF-patients over the past 12 years.

Method: From 2000 to 2012, patients (n=89; 50 male, 39 female) aged between 14 and 57 years were routinely assessed by means of the Cystic Fibrosis Questionnaire – Revised (CFQ-R) during routine outpatient visits (including the assessment of lung function – FEV1%). Patients were in a stable condition and information was shared with them. In 2008 computer based assessment was implemented.

Results: In 428 assessments patients reported a moderate level of perceived treatment burden (mean = 64.55±21.21). In the course of 12 years we found three significant alterations. The first significant decrease was identified in 2001 (mean = 39.68±12.10 vs. mean = 65.70±20.63; p=0.000). In 2008 patients showed an unexpected increase of perceived treatment burden (mean = 32.30±17.28; p=0.000), which significantly attenuated again in 2009 (mean = 64.94±19.94, p=0.000). Perceived treatment burden increases in addition to low lung function (p=0.007) and age (p=0.007), regardless of illness severity and gender. Lung function improved over time (not significant).

Conclusion: Due to changes in prescriptions (i.e. increasing number of nebulized therapies) and despite different levels of treatment adherence, lung function improved over the years whereas perceived treatment burden varies minimally.